



8: Looking after yourself

This section suggests ways to think about your own wellbeing when supporting someone with MND.

The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: **www.mndassociation.org/MNDguides**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Caring and MND:
support for you**

8: Looking after yourself



This section suggests ways to think about your own wellbeing when supporting someone with MND.

Taking care of yourself can seem like an impossible task when facing the challenges of supporting someone with MND.

It is important to look after your own needs, yet you may:

- feel overwhelmed by demands
- have no time for yourself
- have other dependents or children who need you too
- try to always put the needs of the person with MND first
- have no energy left to care about your own needs and wants.

“Advice about looking after yourself, taking breaks and so on, is the most difficult to follow. It’s perfectly sound – we understand the good sense employed – just impossible to accomplish.”

Physical and psychological health can be affected by taking on a caring role. This may result in you being unable to provide support, even if this is still your wish.

As difficult as it may be, there may come a time when you need to ask for and accept support. You may need assistance with care tasks or personal support to manage the emotional demands.

Practical chores, exhaustion and the unpredictable nature of MND may make it hard for you to take time out. Providing care

may be more difficult and intense than you ever imagined. MND is not just about the person diagnosed, it affects you too and you deserve support.

“In effect, you are living two people’s lives.”

You may also feel as if you are losing control of the situation. MND is complex and ever changing. This can be stressful, but taking a practical approach can help you feel calmer and more able to cope.

Think about each difficulty that arises and what could help. Where appropriate, seek advice from the most appropriate member of the health and social care team who support the person with MND. There may be more than one solution, but try the simplest first, if it feels safe to do so. It may do the job and making life as easy as possible is important when you have so much to do.

“When you become a carer, you stop thinking about yourself and your own wellbeing completely. Looking back, I can see how I let myself lose my identity, because I refused to accept or research the help that was available until it was too late.”

Working as part of a team

With the person you support

If you can work as a team with the person you support and be flexible with routines, life with MND may be a little easier to manage.

This is not always possible to achieve. Sometimes, relationships are difficult and MND tends to make this harder. Even where the relationship is close, the person with MND may have problems with speech and communication. This makes it more tiring to remain aware of each other's needs. Discussion takes longer and can be frustrating for you both, but assessment by a speech and language therapist can help. There are therapies to help maintain speech for as long as possible and communication aids to assist when further support is needed.

See Section 2: *What to expect* and Section 5: *What kind of support is available?*

Communication barriers can also happen if you feel tempted to lighten the burden for the person you support. For example, you may keep your own feelings and needs hidden, as a natural protective response. Yet, this is unlikely to help either of you in the long term.

“Understandably, as a carer, you want to praise the person’s bravery and initiative, you don’t want to say ‘help’”

Open communication helps you both to face the challenges ahead as a team and support each other. If the person with MND finds it hard to discuss their condition, a member of the health and social care team may be able to facilitate a difficult conversation.

This can be important if someone has a determined approach to the disease and resists external help. In an effort to make life as normal as possible and keep everything around them the same, the person with MND may:

- be reluctant to use equipment and aids that support disabilities
- unwilling to accept help from visiting care workers
- refuse any form of respite care.

“My wife will not go into respite care...I have guilt thrown at me if the idea is even suggested.”

They may not realise the impact of this on you. As they become more dependent, the more you have to do. There is a limit to anyone's capacity – especially if night care is also needed and sleep is disturbed.

A needs assessment for the person with MND and a carer's assessment for yourself can be useful. Carried out by adult social care services, these assessments work out what your current and future needs are likely to be. You will also receive advice on services in your area. This may also help the person with MND to recognise the value of available support.

See Section 4: *Carer's assessment.*

You and the person you support can have an assessment of your needs together if you wish. This may be helpful in encouraging discussion to gain appropriate support for you both. However, you may find it difficult to be open about the challenges you face as a carer in front of the person with MND. In this case, you can ask to be assessed separately. Either way, try to be honest about your needs.

The assessment process can help the person with MND understand why additional support and equipment may become necessary. Other members of the health and social care team may need to repeat these messages over time.

If the person with MND's behaviour seems to have changed, and they become set on one viewpoint and show a lack of empathy, this

may indicate changes to their thinking. Seek advice from their neurologist or a specialist MND nurse, as there are screening tests that can help work out what is happening. If MND is causing changes to thinking and behaviour, you are likely to need additional support.

See Information sheets 9A to 9C for details about changes to thinking, behaviour and emotions with MND.

With family and friends

Care workers often share responsibilities with other staff and, even on long shifts, they go home and rest. The pressure on you as an unpaid carer can be greater, especially if you live with the person you support, so don't feel afraid or ashamed to ask for help. You may not be able to shoulder everything alone.

“Accept help when it is offered. I am getting better at this. I want to be able to do it all by myself, but I just can't. I won't be able to survive if I do.”

Friends and family may be more willing to help than you think, but unaware of how they can make a difference. Let them know and keep a list of chores to offer if they volunteer help. They may welcome this, as it means they can do something positive in a situation that challenges them too.

Some tasks are easy to give to others, such as:

- washing clothes
- ironing
- preparing a meal
- shopping
- internet shopping
- vacuuming
- gardening chores.

“Don't be afraid to ask for help. It's surprising what people are ready to do, but won't in case they are intruding.”

Some may be able to provide care cover or just keep the person company if you need to go out. This can help you take a break or get tasks done outside of the home.

If you do not have a network of family and friends for support, assessment and review by the health and social care team may help answer a variety of needs. This may result in assistance from care workers, who can help around the home or with personal care for the person you support.

With health and social care professionals

It is important that all professionals involved in support of the person with MND respect you as a member of the care team. Speak up if something worries you. You know more about daily care and the way the disease is progressing than they do.

You may choose to act as an advocate for the person with MND. This means you help to raise awareness of their needs and act as their 'voice' in certain situations. This may include representing their best interests if they become unable to make decisions or communicate for any reason. However, you need consent from the person with MND before professionals can provide you with any of the person's medical information. If you do not wish to act as an advocate, health and social care professionals can assist.

Encourage the person you support to give consent to their GP and health and social care team to share medical information with you. It can help to have a signed letter of consent in case the person with MND becomes unable to communicate for any reason. If you need to seek guidance on how to manage symptoms, this can make these conversations easier. Anything you can do to reduce stress for yourself is important.

Use the health and social care team for your own support too. If you feel there is guidance they can offer, do ask.

See later heading *Health and wellbeing*.

There are many ways the health and social care team can assist if you are under pressure.

“There were weeks when we were going to hospital three separate days to see three different people.”

A good example is asking them to group appointments – if they are working in a co-ordinated way, as part of a multidisciplinary team, this should be possible. This happens at MND care centres and networks, and many neurological clinics. Seeing several professionals in one day will still be tiring for both of you, but avoids multiple journeys and gives time to rest before the next appointment day.

Carers have rights, so feel confident about asserting these if you need help. Following a needs assessment for the person with MND and a carer’s assessment for yourself, you should be linked to wider support and possibly help with care.

See Section 3: *Your rights as a carer* and Section 4: *Carer’s assessment*.

How do I get everything done?

The simple answer is: *don’t even try*.

Taking on a caring role inevitably means taking on more work than you did before. This is likely to increase with MND as symptoms progress and the person you support becomes more dependent.

“It’s a full-time job.”

Instead of trying to accomplish it all, consider whether each task is:

- essential
- important
- needs doing, but not immediately
- would be nice, but not needed.

Be honest with yourself, as there will almost certainly be jobs that are not vital, or that can wait.

“I felt that by doing everything myself, in relative secrecy, I could somehow pretend to the outside world that things weren’t so bad.”

Even if you take pride in doing tasks a certain way, it helps to think about how you work. Being flexible about chores and routines can release time for you and the person with MND to do the things you really want to do.

This is important, as the person you support may have problems with fatigue. There may be better times of day, when their energy is higher – save these times for preferred activities where possible. These might be good times to do things together or for family and friends to visit.

Health and wellbeing

What to look out for

As a carer, your health may be affected. Signs of stress may include:

- extreme tiredness
- irritability
- difficulty sleeping
- headaches
- muscle tension
- unexplained aches and pains
- uncontrolled or repeated bouts of crying.

You may also receive injuries from moving and handling, as the person you support may have mobility problems or experience falls.

How do I manage this?

Let your GP and GP surgery staff know that you are a carer. Most surgeries will then place a marker on your medical record, which helps them monitor and respond to your needs. This may result in:

- more suitable appointment times
- home visits if appropriate
- health check-ups to monitor your wellbeing
- advice on treatment or care for the person you support
- information about support, such as respite care to give you a break
- you being recognised as an expert partner in the care of the person with MND.

Your GP may see signs of stress that could lead to ill-health. Try to take the advice given, even if you feel under pressure.

“I needed someone in authority to tell me that after seven and a half years of caring and not sleeping properly, it was okay to take a break.”

It can help to arrange care cover so you can attend regular GP appointments on your own. This way, you can talk openly about how you feel with the focus on you. Try to prepare for these appointments. You may find the following questions useful:

- Is your health worrying you?
- Are you getting enough sleep?
- Do you have any aches or pains that need to be explored, such as back ache?
- Are you feeling continually stressed or anxious?
- Are your moods consistently low?

- Do you feel isolated or lonely?
- Are you worried about money?
- Is your sex life affected?
- Do you need help with care tasks?
- Do you know how to access emergency services if needed?
- Can the GP help with plans for emergency care cover if you fall ill or have an accident?
- Can the GP advise about local support groups and carer centres?

All of these questions help your GP to build a picture of your needs and advise in an appropriate way.

How can I help myself?

“As a person forever on the go, I have learned to stop. I love to lie on our old tatty green sofa in the kitchen, facing the open doorway, where I can see and smell our lovely garden, now badly in need of cutting back (see, there I go, to-do list starting already). I give myself twenty minutes there sometimes – occasionally I doze, which is not a bad thing. Often the cat joins me and I find his presence oddly comforting. I am learning to take ease when I can. I have to. This is hard for me.”

If you are the main carer, the burden of full-time care should not be underestimated. No-one can be on the go 24 hours a day, seven days a week. Don't feel guilty about looking after your own wellbeing.

It can help to discuss your needs with the person you support, so they understand how MND affects you too.

The following suggestions may help you achieve a better quality of life while caring. Not all of these suggestions will be right for you and there will always be the issue of finding time to look after your own needs. However, if you become exhausted, you may be unable to support the person with MND, even if this is your wish.

Ways to achieve 'me time'	How?
<p>Carer's assessment</p> <p><i>"At the time of the assessment my needs were not as great as now, but extra help has come as needs arise."</i></p>	<ul style="list-style-type: none"> • Ask for a carer's assessment through your local authority, or in Northern Ireland through your local health and social care trust. Assessment enables you to find out about social care services, including respite care and care worker support. <p><i>See Section 4: Carer's assessment.</i></p> <ul style="list-style-type: none"> • Before the assessment, keep a record of what you do, even if you can only find time to do this for a short period. It can help the assessor see the level of support you give. <p><i>See our Care summary in the write-on pages at the back of this guide to help you track care tasks.</i></p> <ul style="list-style-type: none"> • At the assessment give a detailed picture of your needs and how a 'bad day' feels. This may help to achieve the best possible support.
<p>Rest and relaxation</p> <p><i>"Our local hospice can offer massages."</i></p>	<ul style="list-style-type: none"> • Rest when you can and let non-essential tasks wait. • Accept help when offered and use the time for you. • Pace yourself where possible and be flexible with routines. • Try not to set goals or standards that are difficult to achieve. • Is there a day centre or local hospice where the person with MND can have a regular session, such as complementary therapy? You may be able to enjoy a session with them or use this time for yourself.
<p>Breaks and holidays</p> <p><i>"I may need a break in the future and will accept help if offered then."</i></p> <p><i>"He attends a hospice once a week and transport is provided to bring him back."</i></p>	<ul style="list-style-type: none"> • At your carer's assessment, find out about respite care, care worker support and any carer break schemes that may be available at your carer assessment. • If you have support from family and friends, can they cover care for you to have a weekend or week away? • If you don't want to go away alone, think about a holiday with the person you support in accessible accommodation. A change of surroundings can be valuable.

Ways to achieve 'me time'

How?

Hobbies and interests

"I joined a creative writing class and try to cycle there once a week...for those two hours I really don't think about anything else."

- Can family, friends or care workers provide regular cover at a set time for you to attend a social club, course or other activity?
- Can you follow an interest or course of study at home, so you can dip in and out as time allows?
- If the person you support has a nap, is distracted by a film or seems settled, can you occasionally take an hour to do something you enjoy and leave the chores?

Eating well

"I care for my wife 24 hrs a day, but get help three times a day for meals."

- Cook in batches and freeze meals to save on preparation time, or use foods that are quick to prepare.
- If the person with MND has an appointment with a dietitian, ask for advice about your own needs and energy levels too.
- If the person with MND uses tube feeding, there may be a temptation to eat separately if you feel guilty they can't eat by mouth. Discuss this with them, as they may not wish for either of you to feel isolated.

See the *MND Association recipe collection* for ideas on easy to swallow meals for the person with MND, as used by other carers.

Staying fit

"I've never been very good at exercise, but if I'm going to get through this I've got to make some attempt to keep fit."

- Caring can be physical, but it's not the same as focused exercise to meet your personal needs. Always ask your GP for advice before beginning a new exercise routine.
- Exercise may feel tiring at first, but improving your fitness can help to improve energy levels and stamina.
- You may be able to access help towards gym membership through your carer's assessment (depending on your financial assessment).
- If you find it difficult to leave the person with MND, there are lots of exercise routines available on DVD or through the internet. If you are not used to exercise, always select a beginner course.
- Getting fresh air can be important if you spend a lot of time inside with the caring role. Simply going for a walk can help fitness and provide a short break. If the person with MND has a scooter or wheelchair, you may be able to go out and enjoy time together.

Ways to achieve 'me time'	How?
<p>Training and learning</p> <p>"It's not something you choose to do: it's thrust upon you."</p>	<p>Ask the health and social care team for specific training in care tasks if you feel unsure. Working as safely and efficiently as possible can reduce risks and the stress you may feel.</p>
<p>Keeping in touch</p> <p>"As a carer you can feel quite lonely. Making time to be with other carers on a regular basis can help."</p> <p>"I love the MND Association forum. This is a great place to talk to other people about MND and take advice from other carers."</p>	<ul style="list-style-type: none"> • Our branches and groups offer a warm welcome and opportunities to share experiences and tips with other carers and people with MND. • Contact our helpline, MND Connect, to find out your nearest branch or group or look online at: www.mndassociation.org/branchesandgroups • You can visit our online forum at: http://forum.mndassociation.org to view posts or join an online conversation. If you find it difficult to leave the person you support, the forum may be a good way to stay in touch with other carers.
<p>Using technology</p> <p>"I like things that are really easy to access and read online. One click and you know what to do – don't make me keep searching!"</p>	<ul style="list-style-type: none"> • Mobile technology, such as smart phones and tablets, can help you access a wide variety of applications, known as apps. These include apps for carers to share information with other carers, track tasks or schedule appointments. <p>See www.mndassociation.org/apps for links to suggested apps.</p> <ul style="list-style-type: none"> • Apps can also provide a range of facilities for the person with MND, including text-to-speech programmes for communication. • Internet shopping can reduce the need for shopping trips and bring groceries and supplies to your door. • Social media can help you maintain contact with the wider world, friends, family and interests. • If you have internet access, you have instant access to information, including our own about MND. <p>See www.mndassociation.org/publications for downloads of our guides and information sheets.</p> <ul style="list-style-type: none"> • Our online forum provides a safe place to view or share experiences and guidance with other carers and people living with MND. <p>See http://forum.mndassociation.org</p>

Ways to achieve 'me time'	How?
<p>Telecare and environmental controls</p> <p><i>“He would communicate by using his chin to nudge a switch.”</i></p> <p><i>“He had a special TV and computer so he could control things more easily.”</i></p>	<ul style="list-style-type: none"> • When the person with MND is being assessed for their care needs, ask about equipment to send messages to a health monitoring service. If you cannot be with the person at all times, this can ensure assistance in case of a fall or other urgent situations. There may be a charge for this. • Adapted switches and controls can help the person with MND remain independent for as long as possible. Environmental controls can help the person with MND control devices around them, such as the television, telephone, computer and lights.
<p>Giving yourself permission</p> <p><i>“I have had to learn to give myself permission to be good to myself.”</i></p>	<p>It is easy to place your own needs second when caring, but you have the right to look after your own wellbeing too. Not just food, drink, rest and hygiene, but general health, sense of purpose and emotional needs. Try not to feel guilty when you manage to find a little time for yourself. When giving so much, it is okay to claim space for you.</p>
<p>Helping the person with MND to feel secure</p> <p><i>“We didn’t know what MND was, so to have an Association visitor with knowledge about it, to sit and talk with us was so important.”</i></p>	<p>If the person with MND resists external help of any kind, including equipment, assistance from care workers or respite care, you may need professional support to help open discussion. The health and social care team may be able to help the person feel more secure about future care decisions. A joint needs assessment for the person with MND and carer’s assessment for yourself can also be helpful.</p> <p><i>See Section 4: Carer’s assessment and Section 5: What kind of support is available?</i></p> <p>Where available, our Association visitors can also facilitate discussion about needs for both of you and how to access support. Or you can contact our MND Connect helpline for guidance.</p> <p><i>See Section 11: How the MND Association can help you.</i></p>

Key points

- Asking for help, with care tasks or emotional support, does not mean defeat. You are simply acknowledging the breadth of the caring role and that support may be necessary.
- Accept that your needs matter too.
- Find out where to go for the most appropriate type of help.

See Section 5: What kind of support is available?

- Let family and friends know how to help, as they may feel uncomfortable asking what they can do.
- Pace yourself – not all tasks are essential.
- Register as a carer at your GP surgery, so they can better support you.
- Ask adult social care services for a carer's assessment for yourself and a needs assessment for the person with MND (if they agree) to work out how support can be arranged.
- Always keep in mind how you have adapted to huge changes already. We are often capable of more than we realise.

Further information

We produce a wide range of publications about MND and the support that may be needed. The following may be useful in relation to this section:

From our information sheet range:

3A: MND care centres and networks

4A: Communicating about MND with children and young people

6B: Complementary therapies

9A to 9C:

our sheets on changes to thinking, behaviour and emotions with MND

12A to 12D:

our sheets on getting around and travel

13A to 13B:

our sheets on sex and relationships with MND

From our other publications:

Living with motor neurone disease: a guide about MND to help manage the impact from diagnosis onwards and maintain the best possible quality of life.

End of life: a guide for people with motor neurone disease: a candid and comprehensive guide about planning ahead for the later stages of MND and wishes for future care.

How to access publications and further information:

Most of our publications can be downloaded at: www.mndassociation.org/publications or you can order them from our MND Connect helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Connect can also help direct you to external services and providers, and introduce you to our services as available in your area, including branches and groups, Association visitors and your regional care development adviser (RCDA).

See Section 11: How the MND Association can help you for details about our services.

Online forum:

The forum provides an opportunity to share information and experiences with other people affected by MND. Hosted by the MND Association at:

<http://forum.mndassociation.org>

Information for professionals

We provide information to help professionals support people with MND, their families and carers. This can be accessed at:

www.mndassociation.org/professionals

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The full guide can be ordered in hardcopy from our helpline, MND Connect:

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The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis